DOCUMENT RESUME

ED 347 718 EC 301 329

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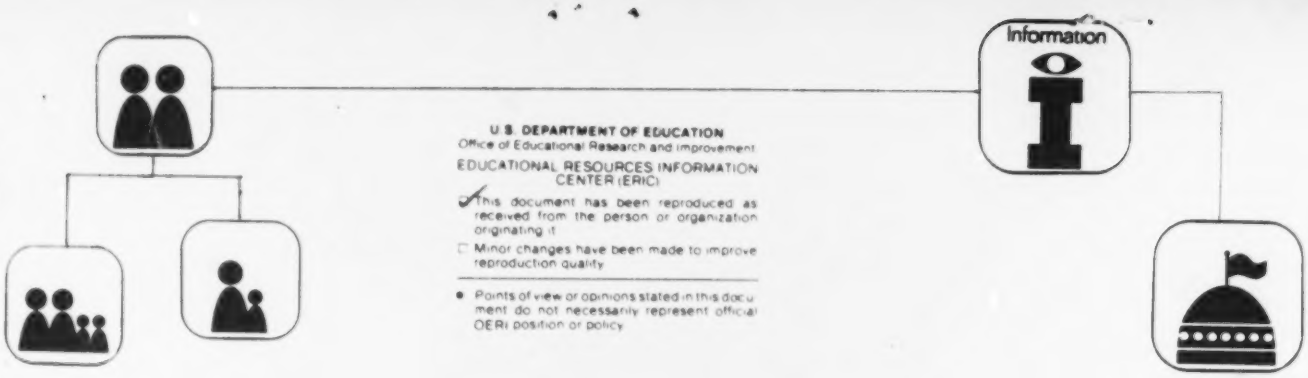
TITLE Implementation of P.L. 99-457: Parent/Professional Partnership in Early Intervention. Background Briefing Report and Meeting Highlights (Washington, D.C., March 16, 1990).
INSTITUTION American Association for Marriage and Family Therapy, Washington, DC. Research and Education Foundation.; Consortium of Family Organizations.
SPONS AGENCY Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Bureau of Maternal and Child Health and Resources Development.
PUB DATE Mar 90
NOTE 40p.; One of a series of monthly seminars conducted by the Family Impact Seminar.
PUB TYPE Collected Works - Conference Proceedings (021)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Agency Cooperation; *Compliance (Legal); Definitions; *Disabilities; *Early Intervention; Educational Legislation; Eligibility; *Family Programs; Federal Legislation; Financial Support; Infants; Needs Assessment; Parent Participation; Preschool Education; State Standards; Toddlers
IDENTIFIERS *Developmental Delays; Education of the Handicapped Act 1986 (Part H); Empowerment; Individualized Family Service Plans

ABSTRACT

This report provides background information and summarizes a 1990 seminar on the parent/professional partnership in the implementation of Public Law 99-457. Topics considered in the seminar included eligibility under Part H of the law, early intervention prior to P.L. 99-457, the process of the legislation, future of the legislation, timing of implementation, interagency collaboration, entitlement issues, the family centered emphasis, finance, transition, voluntary parental participation, case management, special needs children in the care of public agencies, state variations in eligibility, and definition of the family. The background briefing report reviews the scope and service needs of infants and young children with disabilities and their families and describes the emerging field of early childhood intervention. Key components of the Infants and Toddlers Program, Part H of P.L. 99-457, are then presented and the main issues discussed. These include coping with diversity, agency collaboration and coordination, the shared responsibility of education and health, states' definitions of developmental delay, family involvement in the individualized family services plan, cultural competence and sensitivity in working with families, empowering families as consumers, training early intervention personnel, and adequacy of financial resources. A list of relevant federal programs and private sector organizations and 46 references concludes the document. (DB)



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IMPLEMENTATION OF P.L. 99-457:
PARENT/PROFESSIONAL PARTNERSHIP IN EARLY INTERVENTION

March 16, 1990 Hart Senate Office Building, Rm. 708

Panelist: **Carol Berman,** associate director, National Center for Clinical Infant Programs
Robert Silverstein, staff director and chief counsel, Senate Subcommittee on Disability Policy
Sharon Walsh, editor, Early Childhood Reporter and consultant in Part H
Phillip Davis, Ph.D., parent consultant

Moderator: **Theodora Ooms,** Director, Family Impact Seminar

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MEETING HIGHLIGHTS.....pages i to vii
BACKGROUND BRIEFING REPORT.....pages 1 to 29

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IMPLEMENTATION OF P.L. 99-457: PARENT/PROFESSIONAL PARTNERSHIP IN EARLY INTERVENTION

Background Briefing Report
and
Meeting Highlights
by
Theodora Ooms

This policy seminar is one in a series of monthly seminars for policy staff titled, *Family Centered Social Policy: The Emerging Agenda*, conducted by the **Family Impact Seminar**, American Association for Marriage and Family Therapy, Research and Education Foundation, 1100 Seventeenth Street, N.W., The Tenth Floor, Washington, D.C. 20036, 202/467-5114

This seminar was co-sponsored by the Consortium of Family Organizations and funded by the Bureau of Maternal and Child Health and Resources Development, DHHS.

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Implementation of P.L. 99-457:

Parent/Professional Partnership in Early Intervention

Highlights of the seminar meeting held on Friday, March 16, 1990, Senate Hart Building, Room 708. (A supplement to the Background Briefing Report.)

Public Law 99-457, Part H is an extremely ambitious, creative and strongly pro-family piece of legislation stated **Theodora Ooms**, the seminar moderator, in her opening remarks. The many people who helped draft this law had a clear vision, they knew what needs to be done to help infants and toddlers with disabling conditions. Thus, Ooms said, the focus of this seminar is on how to make best practices, standard practices.

Ooms introduced the first panelist, **Carol Berman**, the associate director of the National Center for Clinical Infant Programs who has been a consultant in many aspects of early intervention. She was asked to present the research and medical perspectives that serve as an underlying background to this legislation.

Who are the children affected by Part H of P.L. 99-457 ? Berman began by pointing out that the scope of Part H of the legislation is very broad, and potentially affects all children from birth to age three. However the law specifies two mandated categories and one optional category. The states are mandated to provide a statewide system for early intervention services to (i) all infants and toddlers experiencing developmental delays in five areas of development and to (ii) all those whose diagnosed physical or mental condition results in a high probability of developmental delay. The third, optional, category is very broad and includes all those "at risk" of developmental delay if early intervention services are not provided. And there is considerable uncertainty about how to assess those "at risk" (see pages 15-16 for more detail on states' evolving definitions). The services are in general to be provided at no cost to the parent.

It is difficult to estimate how many children will be served by the law since it is not easy to diagnose developmental problems in early infancy, and a single risk factor---such as a birth injury ---may, or may not, lead to later problems. Moreover the population at need is clearly expanding, though no one knows by how much, as a result of the growing numbers of drug-exposed and HIV babies. Professionals' own estimates of the prevalence of children with vulnerabilities thus vary widely from 3%-26% of the population from birth to three. Berman pointed out that states' choices about whether to include the category "at risk" and how broadly to define "at risk" will have considerable impact on the cost of services to be provided.

Research background of the legislation. Two streams of research had considerable influence on the legislation. First, the studies documenting the extraordinary degree and range of developing capacities even very young infants possessed. Second, studies that assessed the effectiveness of a wide range of ameliorative and rehabilitative medical, educational and social service provided to infants and very young children and their families to promote and enhance their development, known as early intervention, EI, programs.

There has been some tendency to confuse the studies of early intervention programs for handicapped children with those aimed at children whose development was delayed largely due to economic and social "disadvantage." The long term effectiveness of programs for disadvantaged children are clear and well-known. The effectiveness of EI for handicapped children is less clear.

Berman explained that this is partly because the distinction was not consistently made until recently, and because the early EI studies were not consistently well designed. Recent meta-analyses confined to a smaller number of well-designed, controlled evaluations have confirmed the positive benefits of EI for disabled children. Importantly, one of the key factors contributing to positive outcomes is high parental participation (see Shonkoff, Hauser Cram *et.al.* 1988).

Status of early intervention prior to P.L. 99-457. At the time that PL 99-457 was under consideration, the service situation facing families with a disabled infant or young child was not working well. Parents seeking help went from pillar to post and travelled long distances, finding a crazy quilt of demonstration programs dotted around, and duplications and gaps in service. Although many demonstration projects had shown how well services could work, states were only beginning the process of developing comprehensive service delivery systems under P.L. 98-199, legislation amending the EHA which offered incentives for planning, development and implementation of systems. There were gross inequities of service availability between communities and often acute personnel shortages. In addition, the health care professionals who play the most critical role in referral to EI services were too often unaware of EI services or unconvinced of their value.

Early Intervention and the existing health care system. Berman pointed out that the common statement about the need to involve health care professionals in the EI services required by P.L. 99-457 should be reversed; developmental/ educational services need to relate to the health care system. The health care system, whether public or private, is the matrix in which EI services should be embedded. All children, from birth onwards need to have a "medical home." It is normally health care professionals who first identify the disability and/or developmental delay.

Berman concluded that it is interesting to note that at the same time that P.L. 99-457 was being developed (in the education community) a parallel activity was emerging in the Public Health Service. In 1982 the Surgeon General held a workshop to develop strategies for children with special health care needs. She pointed out that workshop's recommendations for "family-centered, community based and coordinated care services for these children are essentially the same as Part H's focus on the state-wide comprehensive, comprehensive, coordinated multi-disciplinary services and the Individualized Family Services Plans. (Note: both streams of activity are brought together in documents reprinted in the 1989 publication of NCCIP, *The Intent and Spirit of P.L. 99457: A Sourcebook*).

Robert Silverstein, the second panelist is currently staff director and counsel for the Senate Subcommittee on Disability Policy. Four years ago he was counsel for the House Subcommittee on Select Education of which Rep. Pat Williams (D-MT) was the Chairman. There Silverstein was deeply involved in the development of P.L. 99-457, and indeed was its principal staff author.

The process of legislation. Silverstein began by noting that those who express surprise at the close correspondence between components of the bill and the lessons of early intervention research must realize this is no mere coincidence. P.L. 99-457 was deliberately drafted to reflect the best knowledge in the field at that point in time.

Three members of Congress provided the key leadership. In the Senate, Lowell Weicker (R-CT) believed that there had been enough talking and planning and that the time had come for handicapped infants and toddlers to be provided with needed services. He saw the Gramm-Rudman law looming ahead and felt that he, as Chair of the Appropriations subcommittee, was in a position at the moment to assure the legislation of funding. Seizing this opportunity he helped push an early intervention bill rapidly through the Senate.

The House, under the joint leadership of Pat Williams (D. MT), Chair of the Sub-Committee on Select Education and Steve Bartlett (R. Texas), minority leader of the committee, undertook an extensive process of consultation with outside groups and individuals as the initial step in their development of the legislation. They decided upon three principles to guide the development of a bill: it must proceed with a bi-partisan consensus; the bill must reflect the best knowledge in the field; and they would get meaningful input from representatives of all those affected by the legislation including the states, providers, parents, and other representatives of infants and toddlers.

Three days of hearings were held, and then a representative group spent 60 hours over the next five days hammering out the legislation. A critical point was reached when it took a site visit to an early intervention program to overcome the initial skepticism of Rep. Steve Bartlett about whether the bill should cover ages birth through age 2. After seeing the need and potential of these programs at first hand, Bartlett became a firm advocate of Part H. This bi-partisan consensus proved critical to the bill's smooth passage though the House. The bill never went to a formal conference since the Senate adopted the House bill, but only after they had had some backdoor conferencing to accommodate some Senate concerns.

Basic themes of the legislation. Silverstein outlined the key principles underlying the bill as follows.

---**Build on Research**: The Congress did not want to reinvent the wheel, but to build on best practices and try to help them spread.

---**Respect the Family:** The most important theme of all was that the bill clearly says the family (not the bureaucracy) must be the focus of this legislation and there must be respect for the family: respect for the family's strengths and for the family as a true partner, not a rhetorical partner, who has the knowledge and information that is critically needed by professionals to try to figure out how best to meet the child's needs.

---**Glue Money**: Part H funds are primarily "glue" money to help states coordinate and collaborate across agencies to deliver improved services. They were never intended to be a million dollar service program.

---**Phase In Period**: Clearly such fundamental changes could only be accomplished with sufficient time allowed to the states to plan properly and make it work.

---**Timeliness**: Young children change very rapidly over time, hence both the initial diagnostic assessment and any disputes must be resolved expeditiously.

---**Grassroot involvements in policy development:** Parents and advocacy groups must be given input in the policy development and evaluation.

Future of the legislation. The bill does not come up for reauthorization until at least next year. Senator Harkin, Chair of the Subcommittee on Disability Policy and the Appropriations Subcommittee has made this legislation one of his top priorities. There is no doubt that his commitment to increase the funding is there.

The third panelist was **Sharon Walsh**, editor of a new newsletter, the *Early Childhood Reporter,* Part H consultant, who previously worked at the National Association of State Directors of Special Education. She was asked to present the perspective of the states.

Timing of Implementation. Walsh began by pointing out the timeliness of this seminar. By April 1st, those states who are on cycle, will be right smack into the middle of their five years of implementation activity. This is a very critical time and one sees in the states a lot of excitement and enthusiasm and a tremendous commitment to making the legislation work. But also as the time grows closer to the deadline, frustrations and anxieties are mounting.

States have been given a good deal of flexibility with how fast they choose to phase in the implementation (they may even opt out for a year if their progress is not "on target"). Nevertheless the majority of states are in the middle of year three, and are expected to apply for a fourth year by this October 1990. By then states have to have all their basic policies in place---all fourteen components of the legislation---and be able to provide multi-disciplinary assessments, IFSP's and case management to all (eligible) children and families. (See page 10-11 for details of the components.) Then before applying for year five, states will have to be able to offer all the services mandated by IFSP's.

Walsh believes that while there is a lot of progress in the states, the next 2-3 years will see a lot of gradual phasing in. State agencies are watching the federal agencies very closely to assess how many new dollar resources they will be putting into Part H, and other related federal programs and to monitor the success of the new interagency agreements, recently concluded by the Federal Interagency Coordinating Council. Similarly, states are being observed and supported by the feds, and by community and state advocacy groups who are pushing them hard.

Some of the key issues she highlighted in the states efforts at implementation are as follows.

Interagency collaboration. States' current structure of operations is the single agency model. In requiring interagency collaboration, this legislation is asking states and communities to drastically change the way they do their business. States who are making the most progress are those who are capitalizing on and integrating their efforts with similar programmatic trends in other service systems e.g. the Surgeon General's initiative and the NIMH Child and Adolescent Service System program which also both call for family-centered, community-based, interagency, coordinated services. (See pages 19-21 for listing of all federal programs that need to be coordinated for an effective system of early intervention.)

Community level. The legislation is deliberately rather silent about preferred structures at the city/ community level. Those states, perhaps as many as three quarters, who are involving the communities in their planning appear to be making the most progress.

Entitlement Issues. In choosing the definition of the eligible population there is tremendous tension between the fiscal realities and implications of certain choices versus doing what is believed best for children and families.

Family-Centered System. Many states are realizing that to develop a truly family-centered system, families themselves must be intimately involved from the initial planning stages through the development and implementation of the program.

Finance. A major presumption of the law is that there are streams of public and private service dollars available to be tapped, but it is essential that states eliminate unnecessary duplication and waste as well as fill in gaps for services. And states are doing this e.g. having one not three agencies screen and assess the child and family. But states are also saying that they need more service dollars, and they need federal leadership to make the existing parts fit together. Coordinated federal leadership is emerging through the Federal Interagency Coordinating Council which has already signed two interagency agreements.

Transition. Families who "age-out" of Part H may experience a sharp bump. The child may or may not be eligible for the pre-school handicapped program, Part B. Even if they are, they will be treated differently as the I.E.P. is child-centered and not family-centered. To avoid this discontinuity, some states are from the start trying to plan Part H type services from birth through age 5. In fact, Walsh concluded that many believe, and hope, that if Part H works, and as its graduate families move through the educational system, what we may see is the goals of Part H gradually adopted throughout the entire education system.

Phillip Davis, Ph.D., the fourth panelist, was introduced by Ooms as speaking from the most important perspective of all, the parents of special needs children. Phil, the father of two special needs children, now works full time as a consultant in implementation of the law, ensuring that it is truly family-centered and involves parents in the policy process.

Davis began by saying he was somewhat amused by all the concern among professionals about how they were going to collaborate, work together, find the financing and solve all the problems to meet the needs of these young children---all within five years! " When my daughter was born, and she didn't move, and our whole world fell apart and there were no resources around to assist us this is exactly the challenge we had. And we made it work. But it wasn't easy. But we learned that while child-focused early intervention works, family-focused EI works better, and family-focused EI in collaboration with professionals works better yet." Davis added EI is cost effective, rewarding and it can be done. But it is essential to look to families and children **as resources,** otherwise it won't work.

Parental participation voluntary. Davis emphasized that one of the key aspects of this legislation is that parental participation is voluntary, parents can decide whether and how they will participate in, for example, the family needs assessment. This means that "if my child is going to be tested and I find the tests to be intrusive or offensive I can be involved in deciding whether the tests should proceed." Thus, a major challenge to the states is to offer services that are responsive to the real needs of families, else they will not participate.

Davis gave as an example of this principle the aborted attempt in his own community in Nevada to establish a respite care program. Respite care is always at the top of any survey of parents' needs. However the program that was set up---a center based program to which parents were supposed to bring their children---was designed without parental involvement and, not surprisingly, parents didn't use it. Taking a child who required three hours to dress to a center was not "respite". If parents had been asked, they would have pointed out that respite care meant having the dollars to be able to bring well trained, trusted caregivers into their homes to care for their children.

Case management. Davis doesn't like the term. He does not like to think of his family as a "case", nor does he like to be "managed". He has always believed that the parent's role in case management, which is what most of them are doing anyway,was greatly undervalued. Apparently, professionals feel that they cannot give the case management responsibility to parents because "someone ultimately has to be accountable for the programs the child receives." But Davis said that as a parent he had always felt he was accountable. The legislation should make possible a range of options including recognizing parents as co-casemanagers, and help them with the case management functions they already perform.

Special needs children in the care of public agencies. In theory, special needs children in the care of public authorities where the accountability is crystal clear should be the best served of all. But Davis believes these children's needs are being much neglected, largely because they do not have effective family advocates. The states and communities thus far have set aside addressing the issue of procedural safeguards and accountability for them.

State variations in eligibility. Variations among states who choose different definitions of eligibility may, Davis thinks, bring up civil rights issues (inequitable access to services). This situation may require a national minimal standard of developmental delay to be established.

Definition of family. Davis pointed out that the law mentions "family" about 54 times yet it nowhere defines family. He felt it was important to use a broad definition, to include as 'family' all those persons who significantly "touched" the child. The definition had implications for implementation since questions were often raised about who should be involved in the IFSP and receive family services: should the eldest, female sibling (who is so often a significant caregiver), should the mother's live-in boyfriend, the divorced, non-custodial parent or the unwed teen father?

Davis concluded by saying that an emerging trend to establish "segregated" centers for these very young special needs children was a major mistake. He felt strongly that we must guard against repeating the errors of twenty years ago. The ages from birth to three is the time when we can be most effective in helping these children and families feel a part of the community and not set off as even more different than they are.

In thanking Davis, Ooms commented that he was a living example of a point Davis himself often likes to make, that we must include fathers when we talk about involving families, not just the mothers (*see additional reference below).

Points Raised During the Discussion.

- A participant felt that the role of state legislatures had not been emphasized enough by the panelists. Several states had already moved far ahead with progressive legislation prior to the federal law, and lots of state legislation is needed to implement mandates of P.L. 99-457. Silverstein replied that in fact the drafters of the legislation had a great deal of respect for what some states had accomplished and sought out existing model legislation in the states to build upon. And they were careful to provide the long phase in period to allow for the needed state laws to be passed.

  Silverstein regretted having to leave the meeting early, but, echoing a theme of the other panelists, challenged the participants, as they struggled with all the complexities of implementation to look upon these issues not as "burdens" but as "opportunities".

- In response to a question about how communities were being defined, Walsh pointed out that the legislation deliberately left this to states to decide rather than impose a single federal definition of a "community". States were approaching this task in interesting ways. About a third were choosing the most expedient route of using the existing boundaries used by one of the key agencies such as the LEA's, local health departments etc. Another 20-30% were using some kind of regional structure; 10-15% had not yet decided how to define "community"; and the remainder were asking communities themselves to define who they were.

  Another related issue, Walsh continued, was whether these communities were to establish parallel lead agencies and interagency coordinating councils at the local level. Most states were doing so with variations on who was chosen to be the lead agency. Some states chose the same lead agency for the communities as was chosen at the state level, some deliberately chose a different agency and some communities made the decision themselves.

- A participant asked about the experiences with states reaching out to find ways of assuring that low income families were served and involved. Berman responded that this clearly

was an important issue. And she was somewhat concerned that in their definitions of developmental delay were not sufficiently recognizing the significance of environmental factors---such as the parent's poverty or mother's depression---factors which both raised the level of risk and made it less likely the child would get to needed services.

Berman then referred to the Mental Health Law Project's study of the extent of outreach to low income minority special needs families in eleven states (see MHLP, 1990). The co-author of the study, Beth Carter, was in the audience, and she confirmed that the study found only spotty evidence of successful outreach and that MHLP was eager to learn about other successful models.

- Davis added that in his experience "we are doing a dismal job of reaching others than middle-class, white America" and we are not even doing a good enough job with them. He believed that public health nurses were the most successful at reaching culturally diverse families, going into their homes and communities and showing great sensitivity and respect and knowledge. He had seen them work very successfully with Native American, S.E. Asian and Hispanic families. Regrettably these public health programs have suffered serious budget cuts. In San Diego there was a successful outreach program in a rural area with professionals and parents paired in teams. Ooms mentioned that in addition to outreach, clearly training of health care professionals in cultural issues was a critical part of the implementation.

- In response to a comment about coordination at the local level, Berman made the point that we must guard against the danger of thinking about Part H as another special 'category' of programs. The exciting promise and challenge of this law is that it is a different way of serving all children. Ooms added that in this respect it parallels other developments in child welfare and mental health services in which some counties and states are experimenting with the "de-categorization" of services.

- A question was raised about all the recent publicity about drug-exposed babies and how the panelists felt they would be affecting the Part H program. Berman said that if HIV and drug-exposed babies and young children are embraced as special needs children, as they should be, then clearly this will increase the numbers served by and hence the costs of the program. And it is important that new federal programs targeting these sub-groups channel these increased resources into early intervention efforts rather than set up new parallel programs. Walsh added that a dilemma for states is whether to include only babies who were born addicted, or all drug-exposed babies in their definitions.

- Ooms referred to Phil Davis' point about the neglect of special needs children in public custody. Many of these children only remain in foster care temporarily. A number or questions need to be addressed about how they can benefit from Part H and who is accountable for them for example: what are the respective rights and roles of the biological parents and the foster parents in the IFSP for example?

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* Additional Reference: May, James. *Fathers of Children with Special Needs: New Horizons.* A Monograph. June 1990. National Center for Family Centered Care, Association for the Care of Children's Health, 3615 Wisconsin Avenue N.W., Washington, DC 20016.

IMPLEMENTATION OF P.L. 99-457: PARENT/PROFESSIONAL PARTNERSHIP IN EARLY INTERVENTION

Background Briefing Report

THE FEDERAL CHALLENGE

An extraordinary, although quiet, revolution is underway in the field of early childhood. The Education for the Handicapped Amendments of 1986 (P.L. 99-457) enshrines into public law the new ideas emerging from research and demonstration programs designed to help infants and toddlers who have special medical and developmental needs and their families. More generally, this act also represents the growing awareness of the value of public investment in improving the lives of the youngest children. A broad and dedicated constituency of parents, professionals, program administrators and public officials helped shape and enact P.L. 99-457 and are now deeply involved in planning its implementation in every state and, eventually, in every county in the nation. Parents of handicapped children are having a strong consumer voice in policymaking and in the delivery of services. This new voice, and the declared program goal of parent/professional partnership, makes this legislation unique.

The goals and components of Part H of P.L. 99-457, the Handicapped Infants and Toddlers program, are revolutionary in a number of ways, most especially in the following three fundamental assumptions that underlie the legislation:

- **Handicapped infants and young children are viewed as whole persons whose needs must be met by service strategies that cut across traditional disciplinary, program and funding categories and boundaries.** Thus the law is designed to provide assistance to the states "to develop and implement a statewide, comprehensive, coordinated, multi-disciplinary, interagency program of early intervention services for handicapped infants and toddlers and their families."

- **The development of the young handicapped child can best be fully appreciated, understood and promoted within the context of their family environment.** This implies that the family needs to be the unit of service not the child alone. Thus the legislation requires that a written Individualized Family Service Plan (IFSP) is developed for each eligible child which must include an assessment of the infant's level of development and needs, and, at families' option, the family's strengths and service needs and expected outcomes of the intervention for the child and family.

- **Services are most effective when parents are respected and empowered as consumers and as treatment team members collaborating with the professionals.** Thus the law requires that the IFSP is to be developed by a multi-disciplinary team to include the parents (or guardian) and that parent representatives must be members of the federal and state coordinating bodies, the Inter Agency Coordinating Councils.

Each of these core assumptions requires fundamental changes in the way early intervention services are financed, administered and delivered and in the orientation and training of professionals who work in the field of early childhood intervention.

The federal challenge to states, communities, parents and professionals is to take these bold, new, complex ideas, tested in hundreds of demonstration programs, and make them standard practice across the nation. Although the basic goals and requirements of the law are far reaching, states are given considerable latititude and flexibility in how they are to be implemented. Studies of the implementation process to date highlight a number of critical issues and questions:

- How are states defining the population eligible for early intervention services?
- What kinds of vehicles, strategies and mechanisms are being developed to encourage and support the necessary cooperation and collaboration between the disciplines, programs and agencies at federal, state and community levels?
- Are there sufficient public and private financial resources and trained personnel available to establish by 1991, and later nurture, these new systems of early intervention in communities across the country, as required by the law?
- How can the new model of family-centered services and parent professional/collaboration be achieved in a pluralistic, multi-cultural, and rapidly changing society? How can policies be developed with sufficient flexibility to accommodate and be sensitive to families who differ greatly in terms of their structure, values, attitudes, coping skills, economic resources and levels of social support?
- Professionals till now have largely assumed that, as the experts, they made the treatment decisions and that their function was to focus all their efforts on the handicapped child. How can they now learn to work with families in partnership, helping them determine their strengths and needs in a respectful, nonintrusive manner, offering them choices, protecting their rights and sharing responsibility with them for decisionmaking?

As background to the discussion of these questions this report will initially review the scope and service needs of the population of infants and young children with disabilities and their families and describe the newly emerging field of early childhood intervention. We then present the key components of the Infants and Toddlers Program, Part H of 99-457 and discuss the main issues emerging from the first planning years involved in its implementation.

INFANTS AND TODDLERS WITH SPECIAL NEEDS

(Source: Hauser-Cram et al., 1988; Meisels and Wasik, 1990; NCCIP, 1989 (a); OTA, 1987)

Who are the infants and toddlers with special needs? There is no simple, clear cut definition of the population of infants and toddlers whose normal development is delayed or threatened and who are considered to be in need of early intervention services. Nor are any national statistics collected about the prevalence of handicap in the first years of life. Estimates of the numbers of infants and preschool children who have special health care needs or developmental problems range from 3%-26% of the population, birth through age 3. The numbers of children who are identified upon entry to school as having some kind of disability are as much as eight times higher than the estimates of disabilities at the time of birth. This is largely because certain problems such as difficulties with hearing, speech, learning or emotional development take some while to emerge before they can be accurately diagnosed.

Infants and toddlers with disabling conditions and developmental delays

Special needs children can be grouped into three broad categories for descriptive purposes. In the first group are those infants who at birth, or shortly after, are diagnosed as having a genetic defect, birth injury or serious chronic illness which results in delayed or abnormal physical or mental development. By one estimate, using a strict standard of definition, 1-2% of all infants are said to be born with some disabling condition. This group includes infants who are mentally retarded who are variously estimated to be between 3-5% of all births; infants with muscular dystrophy; cystic fibrosis; congenital heart disorders or serious heart disease; neural tube defects (e.g. spina bifida); cerebral palsy ; and infants born with serious fetal alcohol syndrome and drug addiction. This group may also include very premature, or low birth weight children who in their first weeks of life experience serious lung disorders, intercranial bleeding and other physical problems that result in damaged and/ or delayed development. Very low birth weight infants (less than 1500 grams, 3 lbs. 5 oz.) are at serious risk of disabilities, with 42% having some neurological handicap or congenital anomaly, and with 14% of these severely affected.

One common factor among these disabled infants is that they need a wide range of intensive medical services at first usually in hospital intensive care units and later at home. Generally they will experience repeated hospitalizations and many of them are highly dependent for several weeks, months or even years upon medical technology such as mechanical ventilators and other devices to assist respiration, apnea monitors, intravenous medication etc. To this group with congenital problems should be added the babies and toddlers who suffer serious illnesses or accidents that cause permanent physical disabilities or brain injuries.

The second group consists of those infants and toddlers who experience delays in development due to sensory impairment, emotional disorders, neurologically based learning deficits or for no clear reason which cannot usually be identified at birth and only become evident some while later.

Infants and toddlers "at risk" of developmental delay

The third group consists of those whose biological circumstances at birth or family environment and later experiences place them at significant risk of developmental delay, which may not become evident until the child enters school. This group is generally considered to include low birth weight infants (defined as weighing less than 2500 grams, 5 lbs 8 oz); babies who "fail to thrive"; babies born to young adolescent mothers; infants exposed in utero to tobacco, alcohol and drugs; and abused or neglected babies. Some would include conditions of extreme family poverty in the category of children who are environmentally at risk.

As many have pointed out, the difficulty with the concept of children "at risk" of developmental delay, is that there is no one-to-one correlation between the risk factor and eventual outcome: numerous studies have shown that single risk factors are not predictive of later developmental problems. For example, an infant at high biological risk such as a very low birthweight infant who had experienced a number of health problems in the intensive care unit, may, if raised in a very positive family environment develop quite normally. Whereas that same infant, growing up in a high stress family environment may have a great deal of difficulty later on.

There is a growing conviction that the concept of multi-factorial risk, namely taking into account the summative effect of a number of risk factors, may be much more useful in both predicting future problems and targeting present intervention services. (This issue has important implications for the implementation of P.L. 99-457, as we discuss on pages 14-15.)

Trends in the Special Needs Population. One of the important policy questions is to determine whether the population of children with special health care needs is growing or is

relatively stable. This is a difficult question to answer since the increased professional and public awareness of the issue and new diagnostic techniques have led to higher numbers of these children being identified at earlier ages. This trend would be expected to continue as the efforts at early identification intensify as a result of the new federal legislation.

There are several other trends that are likely to contribute to future increases in the population of special needs young children. However, the net effects of improved medical technology are not clear. On the one hand, the development of highly specialized and aggressive medical technology in the premature intensive care units has lead to the survival of many more infants and young children with disabilities, many of whom are technology dependent, who would otherwise have died. On the other hand, new technologies under development may also contribute to a lowering of the rates of developmentally delayed newborns if they lead to prevention of prematurity or moderate the crippling lung disease in low birthweight babies.

Two recent trends clearly increase the numbers of handicapped infants. There has been a sharp increase in the numbers of newborns exposed to drugs, especially whose mothers abuse "crack", and these babies are at considerable risk of developmental delay and disability. In addition, a related trend is the small, but sharply rising number of infants exposed to HIV virus via their infected mothers, most of whom are intravenous drug users or partners of drug abusers or bisexual men. It is believed that up to 65% of these babies will themselves contract the AIDS disease. It is not clear what special services will be needed for these infants but, clearly, case management services will be very important.

FAMILIES OF CHILDREN WITH SPECIAL NEEDS

(Sources: NCCIP, (i), (ii), (iii); Turnbull and Turnbull, 1979; O'Connell *et al.*, 1989; Pizzo, 1983 & 1990)

Families of every income level, racial or ethnic group and in every geographic region of the country have children with special health care and developmental needs. However women with certain characteristics are at greater risk of giving birth to children with birth defects or other kinds of disability such as older women, poor women, women who drink heavily or use illegal drugs etc. Although their circumstances and resources are very diverse, as are the needs of their particular children, all these parents share the experience of raising a child with a disability or handicap. This experience has a profound impact on all members of the family---parents, siblings, grandparents and close friends---and almost every aspect of the family's life---financial, emotional and social---is strongly affected.

One must be wary of generalizing or over-simplifying the feelings and experiences of parents who live with the developing handicapped child. Many parents themselves describe the initial shock upon gradually discovering or being suddenly told about the child's disabling condition. For some, this realization is followed by feelings of guilt, blame, anger, despair and helplessness which may continue in roller coaster fashion for years.

Most parents experience the ongoing stress and anxiety involved with obtaining the services their "special" child needs both in the present and the future. And there are the overwhelming demands upon parents' time and energy that caring for many of these children entails, demands that have to be balanced with work and other family responsibilities. But at the other end of the spectrum there are also "moments of victory, joy and relief at challenges mastered, assaults to health overcome, and encounters with hope sustaining breakthroughs" (Pizzo, 1990, p. 669).

Over the past two decades parents of handicapped children have described in interviews, speeches or in print their powerful feelings, harrowing experiences and the host of practical problems and frustrations they encounter as they try to get help for their child and themselves. Several major themes are woven throughout their presentations:

- Too often it is a continuous nightmare for parents to try to learn about what services their child needs, where to find these services and how to pay for them.

- Too often researchers and clinicians focus solely on identifying the risk factors in the child's home environment, and in so doing they "pathologize" and label the family in ways that are highly destructive instead of searching to identify the strengths and resources family members can mobilize to help their child.

- Although services for their "special" child are increasing, the family also needs services for themselves which are much less often available. They need information, counselling, support and, sometimes, therapy and practical services such as financial advice, employment counseling, specialized child care and above all "respite" care to get some relief from the round the clock job of caring for their demanding infant or toddler.

  A recent survey of parents across the state of Arizona highlighted the precarious economic situation of parents of handicapped children who are working poor, and do not qualify for public medical assistance. Often a parent may become unemployed or have to cut back their hours in order to care for their special child, thus not only reducing family income but also losing health care insurance (O'Connell, etal., 1989).

- While parents are grateful for the expertise of professionals and the help they provide, parent after parent provides painful examples of helping professionals who are patronizing and insensitive, blame and label the parents, and who treat them as incompetent or as helpless victims. Such professionals ignore parents' views, knowledge and experience and parents' rights to make decisions and share responsibility for the care of their own children.

Many parents of handicapped children have become activists, banding together to help each other and work for improved services for their child and themselves, for more respect for their own expertise, and to assure their rights as parents. In the last decade, the parent advocacy movement has become a powerful force and has helped to shape the new models of early intervention services and state and national policy. Federal and state policymakers have recognized their role, and provided some limited funding to strengthen parent organizations. Parent leaders have successfully insisted that they are a major resource to their own children and that parents must play a key role in the planning, implementation and evaluation of services to handicapped children.

EARLY CHILDHOOD INTERVENTION

(Source: Barnett & Escobar, 1990; Greenspan and White, 1985; Hauser-Cram, 1990; Meisels & Shonkoff, eds., 1990; Shonkoff and Meisels, 1990; Shonkoff, *et al.*, 1988 ; Smith and Strain, 1988)

In the preface of the new *Handbook of Early Childhood Intervention*, which is destined to become a classic in the field, the editors comment "in little more than a decade it (early childhood intervention) has been transformed from an emerging service with a primitive empirical base, scant funding, and virtually no public mandate to a robust area of theory, research, and practice. Moreover since the passage of the Education for All Handicapped Children Act Amendments of

1986 (Public Law 99-457) early intervention has acquired a growing national audience, increased funding, a promise of more comprehensive programs and services, and unprecedented attention from major state and federal policymaking groups" (Shonkoff and Meisels, eds. 1990).

What are the objectives and principal components of early childhood intervention? What is known about its effectiveness? And how much does it cost?

Early childhood intervention (EI) is a term to describe both a philosophy and a broad field focussed on handicapped children, gifted and economically disadvantaged children. The philosophy, evolving from child development research, emphasizes that infants and toddlers, whether gifted, disadvantaged or handicapped, have an enormous capacity to learn from birth. Providing a stimulating, supportive, educational environment in the years before a child enters school will maximize the child's potential and may prevent the emergence of more severe, and costly problems later on.

While in this report we focus on early intervention services for children with disability or at significant risk of developmental delay, it is important to note that much of the research that supports the concept of EI and the growing base of political support for the field has arisen from studies of preschool programs targeted primarily at disadvantaged children (i.e. low income, minority children) such as the Head Start program, the Perry/Preschool Project etc.

Under the rubric of early intervention are a wide range of programs and services conducted in medical settings, educational pre-school settings, community based centers, offices and families' own homes and encompass diagnostic and assessment, remediation, and education and supportive services. These include, for example, intensive educational outreach in the community to "child-find"; comprehensive neurological and developmental testing; vestibular stimulation for children with cerebral palsy; teaching sign language to a deaf or autistic child; auditory and kinaesthetic stimulation for a low birth weight infant; a program of self-help skills for a mentally retarded child; educational counselling sessions for parents; parent mutual-help support groups; case management services designed to help parents access needed services; respite care etc. Some of these services are provided for only a few minutes a day, or a couple of hours a week, others constitute a full day, full week program. Many different professional disciplines are involved in providing these services including physicians/ pediatricians, public health nurses, nutrition specialists, physical & occupational therapists, speech and language therapists, social workers etc.

Early intervention programs can have a number of objectives such as: to remediate developmental lags; to modify the extent of a specific disability or teach the child ways of compensating for the deficit; and to prevent the development of secondary problems and deficits that too frequently are a by-product of the primary problem. For example substantial emotional or psychological problems may often accompany serious, chronic illness or disability or serious learning problems may follow from a fairly minimal sensory or neurological impairment.

Increasingly, early intervention also targets the family environment aiming to strengthen the parent-child relationship through helping parents learn how to stimulate their nonresponsive child or manage the difficult behavior of the hyperactive child. And through providing other kinds of education, advice, counseling and support services early intervention's major goal is to help the family cope with the extraordinary demands of caring for their "special" child and lessen family stress.

The conventional wisdom in the field of early intervention is that the earlier these programs begin the better; the more comprehensive they are the more effective; that parent involvement is essential to program success; that the intervention must be sufficiently long to have an impact; and that the services be carried out by personnel specifically trained in EI.

Effectiveness of Early Intervention

Now that policymakers are being asked to provide increased resources to early intervention they naturally want to know whether EI programs are effective, and do they reduce public expenditures in the long run? The most encouraging answers to these questions come from preschool intervention programs aimed at disadvantaged children. In this area, there is strong evidence of positive effects on the children in the short run and a couple of well known studies of programs that have positive long term effects and accomplished considerable cost savings as a consequence. These positive findings were often quoted to support the passage of P.L. 99-457 in hearings held on the bill in 1986.

However the questions of program effectiveness have been less well researched in the area of early intervention programs that serve handicapped children. The small number of high quality, well controlled studies do show strong evidence of positive effects. They also pinpoint parent involvement as a key factor in program success. However methodological and other problems limit the significance of the findings of many of the less well designed evaluations.

For example, these studies have usually examined programs that provide only a narrow, limited intervention; relied too much on cognitive measures of success such as I.Q. and ignored measures of social competence; focussed only on the developmental outcomes for the child and ignored program impact on the family's coping skills and adaptability and so forth. In addition studies have generally been funded for only short periods of time and thus long term effects could not be assessed.

For similar reasons, it is difficult to assess the costs, and hence the cost savings of early intervention programs, especially those programs which have many different components and a variety of goals. However some studies, albeit with some methodological limitations, claim dramatic cost savings from early intervention ranging from $4-$7 dollars saved within three years for every dollar spent (Smith and Strain, 1988). Further study of the cost/benefit and cost effectiveness of EI programs for children with biologically based developmental delays are clearly needed.

Overall, the conclusion of one review of early intervention research is that "we should take a rather optimistic, glass half-filled, view toward the existing data". The flaws in the evaluation technology to date seem likely to bias results in the unfavorable direction thus the fact that they have produced some strikingly positive findings "should lead one to be very optimistic indeed" (Greenspan and White, 1985:5). The present challenge to research is to design more comprehensive, well designed interventions and evaluations whose purpose is not to answer the global and too simplistic question, "Does early intervention work?" but to answer the question "What types of early intervention services are most effective for what types of children and families and what are the benefits for child and family?"

The Early Intervention Collaborative Study, a five year study which began in 1987 and is being conducted at the University of Massachusetts Medical Center, is an example of the type of study that needs to be done. It follows a diverse sample of 217 handicapped children and their families who are enrolled in one of 29 participating early intervention programs from age of entry into EI, the youngest beginning around one month, through age five. The study collects a rich body of data through interviews and in home observations. Normally, parents as consumers are seldom tapped to be a resource by researchers. By contrast, a unique aspect of this study is the Parent Advisory Board who provided a great deal of help with the design of the study and with the decision of which child and family outcomes should be measured (see Shonkoff, *et al.*, 1988).

EDUCATION OF THE HANDICAPPED ACT AMENDMENTS 1986, P.L. 99-457, PART H, HANDICAPPED INFANTS AND TODDLERS PROGRAM

(Sources: DOE/DHHS, 1989; Hauser-Cram, *et al.*, 1988; MHLP, 1990, Shonkoff and Meisels eds., 1990; Silverstein, 1989; Gallagher *et al.* eds. 1989)

Background of the legislation

As several commentators have noted, it is quite surprising that such far reaching legislation as P.L. 99-457 was enacted at a time of so little support for expanded federal investment in social programs, and in spite of considerable initial opposition from the Reagan Administration. Although the leadership and sponsorship for this new law came from the education community there were parallel developments occurring in the medical community which have reinforced each other.

Since the 1970 Act (P.L. 90-538) the Department of Education's Handicapped Children's Early Education Program had funded more than 300 demonstration projects, 22 of which had been approved for national dissemination resulting in more than 2000 replications in other sites (Greenspan and White, 1985). In 1976, the landmark legislation, P.L. 94-142 Education of All Handicapped Children's Act established the right to education for all school-aged handicapped children. This law provided some incentives to the states to also serve handicapped children age 3-5. Additional legislation was passed in 1983 to try to encourage states to expand their services to handicapped preschool children, infants and toddlers. While many more children were clearly being served reports suggested that by 1985, the number had "plateaued" and as many as 70-80,000 children age 3-5 were estimated to be unserved. And there was little information about the numbers of infants and toddlers receiving EI services. In 1986 a Department of Education annual report to the Congress summarized the lessons of the demonstration programs as providing convincing evidence that early intervention programs "have demonstrated beyond a doubt the economic and educational benefits of these programs for young handicapped children".

A similar thrust was emerging in the health care community. Parents and professionals of handicapped infants and toddlers were protesting about the fragmentation and gaps in health care and other services for these children, existing services were hard to find and located primarily in high cost inpatient units or tertiary care centers far from their homes. The Bureau of Maternal and Child Health, through numerous SPRANS grants (Special Projects of Regional and National Significance) funded demonstration programs of family-centered, community based systems of health care for special needs children. In 1982, the Surgeon General C. Everett Koop, held a federal workshop, followed by several regional workshops on "Children with Special Health Care Needs". At these workshops the problems and needs of children with special health care needs, and the many gaps and shortcoming in present services were presented and discussed. Many of the recommendations focussed on the need to develop comprehensive, coordinated, community based and family-centered systems of care for these children and their families (Koop, 1987).

In 1986, armed with the research rationale and program experiences, several Members of Congress, with enthusiastic support from professionals in the field and parent advocates, decided to seize the opportunity to draft significant new legislation. The two Congressional leaders were, in the Senate, Lowell Weicker (R-Conn.) Chair of the Appropriations Subcommittee and the Senate Subcommittee on the Handicapped and in the House, Pat Williams (D-MT), Chair of the Subcommittee on Select Education. The effort and work on drafting the bill was firmly bipartisan. Three days of House hearings were held, and once the bill was drafted it proceeded through the Congress quite rapidly.

Brief summary of the legislation

P.L. 99-457 is landmark legislation for infants and young children with disabilities and other special needs and their families. It was proposed, discussed, enacted and signed into law all within the space of six months in 1986. Proposed rules were published in November 1987, and the final regulations were issued in June 1989. The legislation has three main sections.

Title I creates under E.H.A. a Part H, the Handicapped Infants and Toddlers program, which is a new discretionary program to provide financial assistance to the states to 1) "develop and implement a statewide, comprehensive, coordinated, multi-disciplinary, interagency program of early intervention services for handicapped infants and toddlers and their families"; 2) to facilitate the coordination of payment for these services from Federal, States, local and private sources; 3) to expand and enhance the quality of early intervention services.

Title II requires states, by the school year 1991-92 to assure free and appropriate public education for all eligible children with disabilities from the age of 3-5 years in order to receive any federal preschool funds including EHA-B state grant funds for pre-schoolers with handicaps. Title III reauthorizes and strengthens a number of existing programs including the demonstration grants program, grants providing services for deaf/blind children and youth, and the severely handicapped, and grants for regional resource centers, personnel training etc.

Intent, Definitions and Key Components of Part H.
(Sources: Silverstein, 1989; MHLP, 1989; Gallagher, Trohanis & Clifford, eds.1989.)

The preamble to Title I, the Handicapped Infants and Toddlers program, clearly states the four basic purposes of the program, namely:

(1) to enhance the development of handicapped infants and toddlers and to minimize their potential for developmental delay,
(2) to reduce educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after handicapped infants and toddlers reach school age,
(3) to minimize the likelihood of institutionalization of handicapped individuals and maximize their potential for their independent living in society,
(4) to enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps.

The Part H program is for children, and their families, from birth through age two (up to the third birthday) who meet eligibility criteria in two mandatory categories---children with developmental delays and children with diagnosed conditions---and, at state option, an "at-risk" category.

The term developmental delay is elaborated in the law in broad terms as measured by appropriate diagnostic instruments and procedures and informed clinical opinion, in one or more of the following five areas: cognitive development, physical development (including vision and hearing), language and speech development, psychosocial development or self-help skills. Within these broad parameters, each state must establish its own definition including specific criteria and procedures for assessing the degree and type of delay that would ensure eligibility.

Similarly states must identify the diagnosed conditions that have "a high probability of delay". The accompanying Committee Report language, and the regulations, provide some examples of such conditions.

Finally, states are given the option of serving infants "at risk" of having substantial developmental delays and if they choose this option must define "at risk", specifying whether to include only concepts of biological risk or also concepts of environmental risk.

The law defines early intervention services as developmental services, provided under public supervision, at no cost (except where related laws provide for family payments under a sliding fee scale), and are designed to meet the infant or child's needs in any one of the five developmental areas. The law identifies ten types of services that may be included, provided by eight types of qualified personnel and in accordance with the individualized family service plan. The regulations spell out 14 services that must be included (if they are in the IFSP) and 10 professions. The categories of services and personnel are not all inclusive.

Components of the statewide system. The components identified in the legislation that the states must include in their statewide system are as follows.

---the state's definition of developmental delay and its position regarding provision of services to children who are at risk;

---single line of authority vested in a designated lead agency with responsibility to administer the funding, develop interagency agreements, resolve intra-system disputes etc.

---policies and procedures related to financial matters e.g. timely reimbursement of funds;

---a comprehensive system of personnel development and personnel standards;

---policy and procedures relating to contracting with service providers;

---a central directory of services, resources, experts, research and demonstration projects;

---timetables for serving all eligible children;

---a public awareness program;

---a comprehensive child-find and referral system;

---a comprehensive, multi-disciplinary assessment of the needs of the child and determination of the family's strengths and needs using nondiscriminatory procedures;

---individualized family service plans including case management services;

---procedural safeguards;

---data collection system.

Part H Funding and Phase-In Timetable.

The federal government provided $50 million to the states for the first year (FY 1987) funding of the Part H program, $67 million for the second year (FY 1988), and $69.8 million for the third year (FY 1989), and $79.5 million for the fourth year (FY 1990). In general Part H funds are viewed as "glue" money, to be used primarily for activities related to planning, cooperation and coordination needed to implement the goals of the legislation. The monies may be used to provide direct services that are not otherwise provided from other sources and to expand and improve

services otherwise available. (Note: Appropriation levels for Title II, the preschool program, grew from $28 million in FY 1986 to $247 million in FY 1989, and $251.5 million in FY 1990.)

The allocations for each state are based upon census data (numbers of children) and not upon the numbers of handicapped children served. Some believe that this formula provides little incentive to the states to serve increasing numbers of handicapped children. Others feel that it is positive way of encouraging states who do not have the funds to plan and develop improved systems of care for special needs children and their families.

States proceed with the Part H implementation on their own 5 year timetable, and thus states may have somewhat different schedules. In order to receive these monies and participate in the Part H program states must meet a number of general assurances over a phase-in period of five years as follows:

During years 1 and 2 and in any subsequent application, the state must designate a lead agency to administer and supervise all Part H activities. The state must also have established a 15 member Interagency Coordinating Council (ICC), appointed by the Governor, to advise and assist the lead agency. The ICC must meet quarterly and include as members at least three parents of young children (birth through six) with handicaps.

By the beginning of their participation in year 3 states must have adopted a public policy that incorporates all the designated components of the statewide system and provides assurances that such a system will be in place by the beginning of the state's fourth year.

By the beginning of year 4, the state must demonstrate that its system, with all its components are in place and that evaluation, IFSP's and case management services must be available. By the beginning of year 5 onwards, the state must make services available to all eligible infants and toddlers and their families. In effect Part H becomes an entitlement from this point on: the right to these services becomes effective when a state's fifth year application is funded.

There is no obligation on states to apply for Part H funds, but in fact, so far, all fifty states and eligible jurisdictions have done so. Reauthorization of Part H is expected in 1991-92.

Federal Oversight and Assistance to the States

The U.S. Department of Education is the lead federal agency for Part H. The Department's Office of Special Education (OSEP) administers the program, processing state applications and distributing funds. However seven agencies within the Department of Health and Human Services also provide services to handicapped young children. Thus a Federal Interagency Coordinating Council for the Part H program was established to improve collaboration among the ten federal agencies (offices and bureaus) that have a significant role to play in implementation of Part H (see Table I, p.31).The FICC has already signed two interagency agreements indicating general support for collaboration in the implementation of P.L. 99-457.

The expectations and requirements of this complex law create a seemingly overwhelming set of implementation tasks for state governments, local communities, parents and providers. In recognition of their need for help, substantial federal funds are being provided under the law to numbers of public offices and private sector organizations to provide a range of technical assistance services and public information materials (for details see Resources, p. 21). Among the major current sources of this technical assistance are the following.

- A **National Early Childhood Technical Assistance System** (NEC*TAS), funded by OSEP, consists of a consortium of five national organizations which collaboratively

assist states and other organizations in various facets of implementing the law. The NEC*TAS is coordinated by the Frank Porter Graham Child Development Center of the University of North Carolina.

- Assistance to the states, and early childhood professionals is also provided through a network of six **Regional Resource Centers** funded by OSEP and a network of 49 federally funded **University Affiliated Programs** funded through the Administration on Developmental Disabilities. The Bureau of Maternal and Child Health and Resources Development also provides considerable funding for technical assistance activities.

- A network of 50 federally funded **Parent Training and Information(PTI) Centers** provides information and training to assist parents of children with handicapping conditions with fulfilling their various roles in implementation of the law. In addition, an organization called **Technical Assistance for Parent Programs (TAPP)** works to improve and coordinate services to underserved and underrepresented groups of parents with disabilities---notably low income parents and those from minority groups. TAPP provides this information and help through the Parent Training and Information Centers. PTI and TAPP are funded by received federal funding from OSEP.

ISSUES IN IMPLEMENTATION

(Sources: Gallagher, Trohanis & Clifford, 1989; Gallagher, Place & Shields, June, 1989; Gallagher *et al.*, October, 1988; Harbin, Gallagher & Lillie, October, 1989; Harbin, Terry & Daguio, April, 1989; Harbin & McNulty, 1990; HHS/DOE, 1989; MHLP, 1989; Shonkoff & Meisels, eds., 1990)

Early Intervention is a field in which the evolving service technology has, thus far, outstripped the nation's capacity to deliver the services. The challenge of P.L. 99-457 seems a simple one: to find ways to get the services to those who need them. But there are a host of barriers and obstacles to be overcome along the way.

The progress of state implementation of Part H is being closely supported and reported upon by the responsible federal agency, OSEP, other members of the FICC and by a number of the organizations that are involved in providing technical assistance. The Carolina Policy Studies Program and NEC*TAS, are the major organizations publishing a series of reports on the findings of these activities. In addition, a number of network meetings and conferences have been, and continue to be held, which often focus on implementation issues concerned with specific topics, such as physician participation in P.L. 99-457. (See Resources, p. 21.)

The field has generated a wealth of publications which synthesize the research and distill the practice wisdom from the experience of exemplary models and practices. These reports provide a very detailed, and comprehensive vision of the components, processes and procedures of family-centered early intervention services that the framers of the law, and early intervention advocates, hope will be instituted throughout the country. While the end vision is exceptionally clear, the routes to get there remain a confusing tangle.

Some of the major issues and challenges that states and others involved in the implementation process are wrestling with in their extensive planning and start up period will be discussed briefly below. We do not however discuss the important questions about how the Title I and Title II of P.L. 99-457 relate to each other, including the issue of how families and their children make the transition between programs when the child becomes 3 years old and how services will be made available to those 3 year olds who will not be eligible to participate.

Coping with Diversity

The federal law and regulations are highly prescriptive in many areas, particularly with respect to the timetable for implementation, although some areas have been left with a good deal of flexibility for states to interpret. The state policies that are developed need to be sufficiently flexible to accommodate to 1) the wide diversity of family circumstances and resources, desires and plans for their children ; 2) The diverse backgrounds, traditions, and approaches of the ten or more professions that are involved in providing EI services; 3) the different levels between, and within, states of agency readiness, willingness and financial capacity to implement the Part H program.

Agency Collaboration and Coordination

The interest in more effective interagency coordination has heightened in recent years in part due to the pressures of declining fiscal resources, the growing awareness of ineffective bureaucracies, evidence of duplication and gaps in services, rising consumer demands, and a growing awareness of the interrelatedness of human needs, and the negative impact of fragmented, categorical programs on the family system.

At state level numerous agencies and bureaus are responsible for the delivery of some type of early intervention services, in some states more than a dozen. P.L. 99-457 gives high priority to the concept of coordination between these agencies and collaborative efforts between the diverse programs and professionals that deliver these services.It requires the states to establish a lead agency to be responsible for making the coordination happen. A study of states' implementation after the first year found that the areas of least progress related to financial issues and interagency coordination.

While the law establishes some structures to facilitate the required coordination between the various education and health related agencies and professionals, it did not spell out the "why" or the "how" of coordination. And while there have been many calls over the years for interagency cooperation in the human services, the full complexity of the concept has not been well understood. Too often coordination is supposed to result simply from the establishment of a coordinating committee. Flynn, Harbin & McNulty have developed a multi-dimensional, interactional, developmental paradigm that contain six broad dimensions involved in effective interagency coordination (Harbin & McNulty,1990).

---specific personnel responsible for facilitating coordination;
---climate of support (policymakers, professionals and the public);
---level of resources (money, people, facilities);
---agency policies that may compete and conflict with each other;
---process vehicles to facilitate necessary communication, planning and mechanisms for conflict resolution; and,
---agency structure (rigidity versus flexibility).

Mobilizing all these dimensions constructively to nurture the long, slow, process of genuine interagency planning and cooperation is the major challenge of P.L. 99-457.

Disparate and conflicting policies at the federal level are also a major barrier to effective interagency coordination. It has been suggested that federal agencies need to undertake the same rigorous process of examining their conflicting policies that they are presently requiring of the states. Many hope that the FICC will assist in such a task.

Education and Health: A Shared Responsibility
(Sources: American Academy of Pediatrics, November 1988; Georgetown University Center for Child Development, June 1989; Martner & McGrab, 1989; Schrag, 1989; Wenger, *et al.*, November 1989)

A central underlying tension in achieving interagency coordination is that the field of EI, at federal, state and local levels, is essentially a responsibility shared between education and health, with each area having its own traditions, professionals disciplines and established policies and practices that differ considerably from one another. And in spite of many efforts to bridge this division it remains a considerable barrier.

Twenty two states have designated education, another third of the states have designated a health or mental health agency, and other states have chosen a variety of human service/ human resources agencies to be their Part H lead agency. Three states have designated inter-agency committees as the lead agency (Texas, Rhode Island and Maine). Maryland has chosen the Office of the Special Secretary for Children, Youth and Families in the Governor's Office to be the lead agency. Each lead agency has designated an individual to be the Part H Coordinator.

Although Part H is clearly intended to be an interagency program, P.L. 99-457 is an education law, and as such, health professionals feel that they, and medical issues generally, are allocated a somewhat secondary role in the provisions of the law. And yet health care personnel have a vital role to play in the early identification of children with special needs. Their knowledge of early intervention resources are essential to prompt referral. Physicians are the key players in assuring that all handicapped children are provided with a continuum of medical services and the "medical home" that they need. The Academy of Pediatrics in collaboration with the Bureau of Maternal and Child Health is taking some steps, including preparing publications to help pediatricians and other health care personnel participate constructively in the planning and implementation of the law.

Similarly, the law does not address mental health prevention and treatment services directly nor did it spell out the involvement of professionals with expertise in child and family mental health. Hence, the federal agency responsible for child mental health, the Child and Adolescent Service System Program (CASSP/ NIMH) has prepared an issues paper and conducted a tri-state study focusing on mental health roles in implementation of Part H.

States Definition of Developmental Delay
(Source: Harbin, Terry and Daguio, 1989)

States were quick to tackle the difficult task of developing their definition of developmental delay and deciding whether to include the population of infants and toddlers "at risk". However the solutions they chose raise a number of questions. In June 1988, a telephone survey conducted by the Carolina Policy Studies Institute Program, found that 28 states had completed their definition and over half of these were planning to include children "at risk". Choosing to exercise this option has major fiscal implications for these states since it greatly increases the numbers eligible for Part H services.

Analysis of the definitions and criteria that the states had developed by June 1988 revealed that most were relying heavily on psychometric approaches for assessing developmental delay (i.e. standardized tests) and were using percentages, or number of months, delayed as the criteria for determining eligibility. States varied considerably in the level of delay needed to be eligible, ranging from 20-50% delay.

Those states who chose to include "at risk" infants and toddlers in their eligible pool, appeared to be relying heavily on a single factor approach to determining "at risk". States cited 53 different criteria for assessing biologic risk and 36 different criteria for assessing environmental risk.

Concern has been expressed that these definitions and criteria do not pay sufficient attention to clinical judgement, that it is not appropriate to derive percent delay scores from standardized instruments used for testing the very young. Further the general professional consensus is that single factor risk assessments are a poor measure of actual risk.

The variability of states' definitions raises another concern that is perhaps unavoidable, namely that families who move to another state are likely to find themselves suddenly losing (or gaining) eligibility for EI services.

Family Involvement in the Individualized Family Services Plan
(Sources: Bailey and Simeonsson, 1988; Bailey, 1989; Dunst, Trivette & Deal, 1988; Gallagher, Place & Shields, June 1989; McGonigel and Garland, 1988; Johnson, McGonigel & Kaufmann, 1989; Krauss and Jacobs, 1990; Place *et al.*, 1989, Silverstein, 1989)

A major priority for P.L. 99-457 is to strengthen and empower the handicapped child's family. "Congress wanted the language of the bill to reflect our utmost respect for the family. The word 'family' must appear ten to fifteen times throughout the legislation. This was intentional. Congress was trying to say 'Respect the Family'" (Silverstein, 1989, p. A-3).

The IFSP grew out of the decade's experience with the Individualized Education Plan (IEP), established in the Education for All Handicapped Children's Act, P.L. 96-142, in 1976. In the IEP parents are supposed to be present at the discussion of the plan but they seldom played a role in its development, their part in implementation was not required to be spelled out and the family's own needs for services were not addressed. The IFSP moves the concept of parent involvement to front and center and envisages the parent as an integral part of the assessment and treatment team.

States may determine how to implement the basic procedures for the IFSP outlined in the legislation. It is said that no provision of the law is producing more anxiety and controversy nor more excitement and hope than the IFSP. Concerns center around whether the IFSP process requirements---especially the determination of family's needs and strengths---will be experienced as intrusive and judgmental; whether families will have genuine choices about the services they and their child receive and whether they can choose how much they wish to be involved. There is also concern about confidentiality and due process.

Many questions are also being raised about the role of the case manager who is specified in the legislation as the person responsible for implementation of the IFSP. Some parents have objected indeed to the very term, not wanting to be thought of as a "case" nor wanting to be "managed". Parents want to know whether they can choose the case manager, how much power the case manager will have, and how they will be trained.

There are some excellent new publications available that recommend specific guidelines and practices for the IFSP, based on best practices, and suggested answers to these questions. These materials exemplify the goals of sensitivity, empowerment, respect and parent/ professional collaboration (see Sources above).

However there is general consensus that a very wide gap exists between these best practice models of family involvement and the actual practice out in the real world. Studies of personnel preparation reveal minimal or no attention paid to the family context of disabled children and little teaching of the skills needed to work in partnership with parents (Bailey et al. 1990). A major

challenge for the states therefore is both to develop their own IFSP guidelines based on these best practices and find ways of disseminating these models in the field, through planning intensive and widespread in-service training.

Cultural competence and sensitivity in working with families
(Sources: Anderson & Fenichel, 1989; Georgetown University Child Development Center, 1989; NEC*TAS, 1989; Shonkoff and Meisels, 1990; Vincent *et al.*, 1990.)

One issue that is highly relevant to training providers for the IFSP that has received scant attention in the literature until recently is how early intervention addresses the structural and cultural diversity of families. Providers of these services need to be wary of stereotyping families' roles and responses and fitting all families into an ideal model of behavior. Different racial and ethnic groups in particular vary considerably in their attitudes towards disability and illness, the ways they express pain and disappointment, their attitudes about child rearing, helping professionals and what their own role should be in EI services. In some cultures for example, it is normal for grandparents to play the predominant role.

While providers need to become much more sensitive to these cultural differences they must be wary of stereotyping members of particular racial/ ethnic groups: differences of income, education, region, and degree of acculturation account for substantial diversity between members of the same race or national origin.

Empowering Families' as Consumers

As noted, Part H legislation spells out a number of ways that parent representatives are to be included in policy planning and development involved in implementation of the Part H program. While parents have been appointed to the federal and state ICCs there has been no study to date of their involvement, or any assessment of the policies needed to facilitate their participation in these meetings such as reimbursement of transportation expenses or for days lost at work, provision of child care etc. These are issues that are particularly important for low income parents.

Field reports suggest that parent involvement is sometimes of a token nature, and that parents are often not truly regarded as equal members of the team. Further the impressions is that in many areas most parent representatives on the ICCs are from middle income, white America. Vigorous efforts to reach out to facilitate the participation of low income and minority parents have been few and isolated. There are however a number of organizations dedicated to strengthen this effort---for example, TAPP and MHLP. (See Resources p. 21.)

Training Early Intervention Personnel
(Sources: Bailey, 1989; Bailey et al. 1990)

The lack of qualified personnel, trained in early intervention, is generally considered to be one of the most serious barriers to states making progress in implementation of P.L. 99-457. And yet the requirements for family assessment, development of the IFSP, and case management services means that professionals from multiple disciplines must be trained to engage in these new activities. Several studies report that between 70-80% of the states report severe shortages of trained personnel to work with handicapped infants and toddlers and a serious lack of personnel preparation programs. Several factors contribute to these shortages including the lack of specialized professional pre-service training in infant and toddlers and in the practice of collaborative care within the major disciplines involved in early intervention; inadequate financial incentives to specialize in EI or attract new recruits into the profession; few in-service training programs for paraprofessionals or professionals already working in the field.

Adequacy of Financial Resources
(Sources: DOE/DHHS, 1989 ; Fox, Freedman and Klepper, 1989; Fox & Yoshpe, 1987 & forthcoming)

A basic assumption of the Part H legislation is that the states would be able to identify sources of funding in other publicly funded programs or in the private sector to pay for the increased services that would be a result of the new program emphasis on serving infants and toddlers and their families. Thus the Part H funds are to be used for service dollars only as a payer of last resort.

The law mandated that the Secretaries of Education and Health and Human Services conduct a joint study of the federal funding sources currently available to pay for early intervention services. The report emanating from this study identified sixteen federal programs, dispersed throughout the two Departments which have "significant potential to contribute resources toward the successful implementation of a statewide system of early intervention services" (DOE/DHHS, 1988, p.5). However, the report points out that only the new Part H program targets funds specifically for early intervention services. In the remaining 15 programs, early intervention services are only one of many potential, and competing, uses of the federal funds.

These sixteen programs represent a broad array of funding mechanisms, considerable variation in the degree to which states can control the disbursement and targeting of funds, and wide range of eligibility criteria. This disparate patchwork of available funds represent an enormously complex challenge for inter-program and interagency coordination if they are to be successfully tapped for funding Part H. (These sixteen programs, and an additional two programs enacted since 1987 are listed below on pages 19-21)

The report also identified a second group of programs that are not meant to provide funding for direct services but that aim to improve the quality of EI through providing funds for research, demonstration, technical assistance, information exchange, and personnel training projects.

Several studies have pointed to the underutilized potential of the Medicaid program to fund EI services for eligible and medically needy children if more states were to pick up options for expansion of medicaid coverage which a few states have already done. The EPSDT (Early Periodic Screening, Diagnosis and Treatment) program is an especially important source of coverage for low income children who are at risk or handicapped. Recent Medicaid and EPSDT changes as a result of OPRA'89 hold the promise of expanded funding. Recent amendments to the Title V Maternal and Child Health block grant program can also be tapped for coverage of some early intervention services, specifically case management services.

The majority of children are privately insured, and thus private insurance represents a substantial, but largely untapped funding resource for handicapped children's health related services. However about 35% of poor and near-poor children lack insurance coverage at some time during the year, and large numbers of others are under-insured. For them, proposals to mandate health insurance, or require coverage of benefits called for under federal programs would be another solution.

It is very difficult to estimate the extent of any shortfall in EI services funding that the states will be facing in the near future even after these other sources of funding are fully tapped. Projected costs estimates of EI services required under Part H are still few and far between, although they are expected to be developed in the near future by NEC*TAS as states are now settling on their definitions of the eligible population.

FEDERAL PROGRAMS PROVIDING SUPPORT FOR EARLY INTERVENTION

(Adapted from *Meeting the Needs of Infants and Toddlers with Handicaps,* Report to the Congress by the Department of Education and the Department of Health and Human Services. This report compiled a list of sixteen federal programs which provide funding for direct services that "have significant potential to contribute resources toward the successful implementation of a statewide system of comprehensive, coordinated, multi-disciplinary, interagency programs of early intervention services." The report also listed federal programs which provide grant support for activities. The Report provides more detailed information on each program based on their status as of December, 31 1987.)

DEPARTMENT OF EDUCATION

Handicapped Infants and Toddlers Program, authorized by the Education of the Handicapped Act Amendments 1986. Formula Grant. Administered by Division of Educational Services, Office of Special Education Programs (OSEP), Office of Special Education and Rehabilitative Services(OSERS).

Chapter 1 Handicapped Program, authorized by the Education Consolidation and Improvement Act of 1981 (Chapter 1). Formula Grant. Administered by Division of Assistance to States, OSEP/OSERS/DOE.

Services for Deaf-Blind Children and Youth, authorized by the Education of the Handicapped Act, Part C, Section 622. Discretionary Grant. Administered by Division of Educational Services, OSEP/OSERS/DOE.

Assistance for Education of All Handicapped Children, authorized by the Education of the Handicapped Act, Part B. Administered by Division of Assistance to States, OSEP/OSERS/DOE.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Head Start Program, authorized by the Head Start Act. Formula allocations to states and discretionary grants to local Head Start agencies. Administered by Head Start Bureau, Administration for Children, Youth and Families (ACYF), Office of Human Development Services.

Medicaid programs, authorized by the Social Security Act, Title XIX. Federally-matched entitlement. Administered by Health Care Financing Administration (HCFA).

Maternal and Child Health Block Grants, authorized by Social Security Act, Title V. Block Grants. Administered by the Office of Maternal and Child Health, Bureau of Maternal and Child Health and Resources Development (BMCHRD), Health Resources and Services Administration (HRSA), Public Health Service (PHS).

Child Welfare Services Program, authorized by the Social Security Act, Title IV-B. Formula Grants. Administered by ACYF/OHDS.

Developmental Disabilities Basic State Grant Program, authorized by the Developmental Disabilities Assistance and Bill of Rights Act. Formula Grant. Administered by the Administration on Developmental Disabilities, OHDS.

Alcohol, Drug Abuse and Mental Health Block Grant, authorized by the Public Health Service Act, Title XIX. Block grant. Administered by the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA), PHS.

Community Health Centers, authorized by the Public Health Service Act, Section 330. Discretionary grant. Administered by Bureau of Health Care Delivery and Assistance, (BHCDA), HRSA/PHS.

Indian Health Service, authorized by the Snyder Act of 1921 and Indian Health Care Improvement Act. Discretionary grant. Administered by Indian Health Service, HRSA/PHS.

Migrant Health Service, authorized by the Public Health Service Act, Section 329. Discretionary grant. Administered by BHCDA/HRSA/PHS.

Preventative Health and Health Services Block Grant, authorized by the Public Health Service Act, Title XIX. Block Grant. Administered by the Center for Disease Control, PHS.

Health Care for the Homeless, authorized by the Stewart B. McKinney Homeless Assistance Act. Three discretionary grants and one block grant. Administered by BCHDA/HRSA & ADAMHA/PHS.

Social Services Block Grant, authorized by Social Security Act, Title XIX. Block grant. Administered by Office of Policy, Planning and Legislation (OPPL), OHDS.

1990 Update:
Since this report two additional federal assistance programs have been enacted which also have potential for funding services to handicapped infants and toddlers. They are:

Temporary Child Care for Children with Disabilities and Crisis Nurseries Grants, authorized by the Children's Justice and Assistance Act of 1986, Title II through FY 1991. Discretionary grants. The demonstration grants are to be used to provide temporary nonmedical child care for children with special needs (often referred to as respite care) and for crisis nurseries for abused and neglected children or children at risk. The program was first funded in FY 1988 at the level of $4.9 million. It is administered by Administration for Children Youth and Families, OHDS/DHHS.

Abandoned Infants Assistance Grants, authorized by the Abandoned Infants Assistance Act of 1988. Discretionary grants. First funded in FY 1990 at $10 million which was then reduced as a result of sequestration. The funds are to be used for demonstration grants to public and nonprofit private organizations for programs and a broad range of related services providing foster care and residential care for the so called "boarder babies". It is administered by ACYF/OHDS.

EXAMPLES OF FEDERAL PROGRAMS AFFECTING THE QUALITY OF EARLY INTERVENTION PROGRAMS.

(Several federal programs were identified in the joint DOE/DHHS report, cited above, which fund discretionary grants to develop model, demonstration programs, replication (outreach) of model programs, research, personnel training and technical assistance in the area of early intervention. These grants are often for limited periods of time. The report's listing is adapted below.)

DEPARTMENT OF EDUCATION

Clearinghouse-Dissemination. Administered by the Division of Educational Services, OSEP/OSERS.

Handicapped Children's Early Education Program (HCEEP). Administered by Division of Educational Services, OSEP/OSERS.

National Institute on Disability and Rehabilitation Research Projects. Administered by OSERS.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Child and Adolescent Service Systems Program, (CASSP) administered by National Institute of Mental Health, ADAMHA/PHS

Clinical Research on Child Health, Administered by the Center for Research on Mothers and Children and the Intramural Research program, National Institute of Child Health and Development, HRSA/PHS.

Special Projects of Regional and National Significance (SPRANS), administered by the Division of Maternal and Child Health, BMCHRD/HRSA/PHS.

University Affiliated Programs Training, administered by the ADD/OHDS.

RESOURCES

This listing of selected private sector organizations that provide information, technical assistance, advocacy and/or conduct studies related to Part H, P.L. 99-457 and early intervention in general is by no means exhaustive.

NATIONAL EARLY CHILDHOOD TECHNICAL ASSISTANCE SYSTEM (NEC*TAS)

NEC*TAS is a collaborative system of six organizations, funded by the Office of Special Education Programs, U.S. Department of Education. Its primary mission is to design and provide technical assistance to states and others involved in implementation of Part H and in the development and provisions of improved services for children with special needs (birth through eight) and their families. As a secondary focus it provides help to the demonstration and outreach projects funded under the Handicapped Children's Early Education Program and to other professionals and parents. The consortium's activities include: developing printed materials, conducting workshops, conferences and meetings, providing on-site and telephone consultations, information referral and networking. The six organizations are assisted by an advisory group, topical-based expert teams, and external evaluators.

NEC*TAS Coordinating Office and prime contractor:

Frank Porter Graham Child Development Center
University of North Carolina at Chapel Hill,
CB# 8040, 500 NCNB Plaza
Chapel Hill, NC 27599
(919) 962-2001
Contact: Pascal Trohanis

Other members of the NEC*TAS collaborative system and sub-contractors are:

Child Development Center, Georgetown University
3800 Reservoir Road, N.W.
Washington, DC 20007
Contact: Roxanne Kaufman (202) 338-1831 or Phyllis McGrab (Director) (202) 687-8837 /8635

Department of Special Education, University of Hawaii at Manoa
1776 University Avenue
208 Wist
Honolulu, HI 96822
(808) 948-6449 or-7956
Contact: Kathleen Curry

National Association of State Directors of Special Education (NASDE)
2021 K Street, N.W.
Washington, DC 20006
(202) 296-1800
Contact: Patti Place

National Center for Clinical Infant Programs (NCCIP)
2000 14th Street
Suite 380
Arlington, VA 22201
(703) 528-4300
Contact: Patti Biro or Ellie Szanton (Director)

National Network of Parent Centers, Inc.
c/o Federation for Children with Special Health Care Needs,
312 Stuart Street, 2nd Floor
Boston, MA 02166
(617) 482-2915
Contact: Martha Zigler or Evelyn Hausslein

ASSOCIATION FOR THE CARE OF CHILDREN'S HEALTH (ACCH), National Center for Family-Centered Care.

ACCH has recently been awarded a five year grant from the Bureau of Maternal and Child Health and Resources Development to establish the National Center for Family-Centered Care. The center will be one of ten national centers funded by MCH to promote family-centered, community based, coordinated care for children with special health care needs and their families of all ages. Among other activities the Center will gather and disseminate successful family-centered approaches, many of which emanate from the field of early intervention.

National Center for Family-Centered Care
Association for the Care of Children's Health
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
(202) 244-1801
Contact: Mary McGonigel (Associate Director)

CAROLINA INSTITUTE FOR CHILD AND FAMILY POLICY, Frank Porter Graham Child Development Center (FPGCDC).

The Carolina Institute for Child and Family Policy, is one of two institutes at the FPGCD Center which is working on aspects of implementation of Part H. The Child and Family Policy Institute has a cooperative agreement with OSEP to conduct ongoing studies of the implementation of Part H, the Infant and Toddlers Program, focusing on policy issues. The program publishes a series of working papers and policy alerts reporting on the progress of implementation.

Carolina Institute for Child and Family Policy
Frank Porter Graham Child Development Center
University of North Carolina at Chapel Hill
CB# 8040, 300 NCNB Plaza
Chapel Hill, NC 27599
(919) 962-7374/7369
Contact: James Gallagher (Director) or Gloria Harbin

CAROLINA INSTITUTE FOR RESEARCH ON INFANT PERSONNEL PREPARATION,
Frank Porter Graham Child Development Center

The Carolina Institute for Research on Infant Personnel Preparation is one of two institutes at the FPGCD Center working on aspects of implementation of Part H. Under a cooperative agreement with OSEP they focus on personnel preparation for professionals from all the different disciplines who provide services to handicapped infants. Their activities initially focussed on assessing the status of pre-service and in-service personnel preparation. The current major thrust is to work with states to design and conduct in-service training programs for personnel to implement the requirements of Part H. Future activities will include the development of materials to assist professionals conduct infant assessment.

Carolina Institute for Research on Infant Personnel Preparation
Frank Porter Graham Child Development Center
University of North Carolina at Chapel Hill
105 Smith Level Road, CB# 8180
Chapel Hill, NC 27599
(919) 966-4257
Contact: Sharon Palsha (Director) or Don Bailey

COUNCIL FOR EXCEPTIONAL CHILDREN (CEC), DIVISION OF EARLY CHILDHOOD

In January-March 1990, in cooperation with the Office of Governmental Relations, the CEC Division of Early Childhood held three regional hearings in Florida, Arizona and Missouri for Division members and other early childhood personnel. The purpose of these hearings was to assist Congress in understanding the issues involved in implementation of P.L. 99-457, reauthorization of Part H in 1991-1992 and introducing potential amendments to Section 619 on the Education for Handicapped Act. Each hearing was followed by a Political Action Network Training session for division teams for follow-up advocacy activities.

Office of Governmental Relations, Council for Exceptional Children
1920 Association Drive
Reston, VA 22901
(703) 620-3660
Contact: Jo Ballard

EARLY CHILDHOOD REPORTER, LRP Publications

The Early Childhood Reporter: Children with Special Needs and Their Families, is a new monthly newsletter, first published in January 1990, whose purpose is to report on the implementation of PL 99-457 and related developments to public officials and professionals involved in early intervention at state and local levels.
(Subscription orders to LRP Publications, 1035 Camphill Road, Ft Washington, PA 19034. (215) 628-3133. $125 for one year.)

Early Childhood Reporter, Editorial Offices
421 King Street
P.O.Box 1905
Alexandria, VA 22313
(703) 684-0510
Contact: Sharon Walsh (Editor)

EARLY INTERVENTION ADVOCACY NETWORK, Mental Health Law Project.

The Early Intervention Advocacy Network, at the Mental Health Law Project focuses primarily on three areas of information and advocacy: 1) access for low-income and minority families to appropriate EI services, 2) protection of children's and families' rights, and 3) building a national advocacy network to broaden and strengthen statewide constituencies to support the Part H program. Among other activities project staff conduct training at meetings, publish Alerts for the Network and conducted a survey of eleven states' progress in implementation.

Early Intervention Advocacy Network, Mental Health Law Project,
2021 L Street N.W.
Suite 800
Washington, DC 20036
(202) 467-5730
Contact: Beth Carter or Margaret Lorber (Co-Directors).

FAMILY ENABLEMENT PROJECT, Western Carolina Center

The Family Enablement Project, Family, Infant and Preschool Program, Western Carolina Center is funded under a grant from OSEP to provide training and outreach activities to states Lead Agencies, Interagency Coordinating Councils and early intervention programs. The Center is one of the pioneers in developing family centered intervention models and assessment instruments designed to support and strengthen the functioning of families with disabled infants and toddlers.

Family Enablement Project
Family, Infant and Preschool Program
Western Carolina Center
300 Enola Road
Morganton, NC 28655
(704) 433-2877
Contact: Carl Dunst (Director)

FEDERATION FOR CHILDREN WITH SPECIAL NEEDS/ PARENT PROGRAMS

The Federation for Children with Special Needs operates a number of programs that aim to provide information and technical assistance to parent organizations and individual parents. These include:

Parent Training and Information Project (PTI) is a federally funded network of over 50 centers offering a variety of statewide services to parents of special needs children and professionals who serve them. The services include workshops, a quarterly newsletter, resource library and speakers bureau.

Technical Assistance for Parent Programs (TAPP) was originally established under the 1983 Education of the Handicapped legislation and refunded under P.L. 99-457. TAPP provides technical assistance to the PTI centers through four regional TAPP Centers, in Tacoma, Minneapolis, Concord, NH and College Park, GA. Throughout the many services the TAPP centers provide there is a special emphasis on reaching out to those families whose children are least likely to be served.

Federation for Children with Special Needs
312 Stuart Street, 2nd Floor
Boston, MA 02166
(617) 482-2915
Contact: Martha Zigler

NATIONAL INFORMATION CENTER FOR CHILDREN AND YOUTH WITH HANDICAPS (NICHCY)

The National Information Center for Children and Youth with Handicaps is a federally funded national information clearinghouse operated by Interstate Research Associates, Inc. It provides information to assist parents, educators, caregivers, advocates and others in helping children and youth with disabilities become participating members of the community.

In addition to responding to personal requests for information, disseminating fact sheets, a regular News Digest and other publications on specific topics NICHCY staff also design workshops, and coordinate resource sharing between groups. Single copies of their publications are distributed free.

National Information Center for Children and Youth with Handicaps
P.O. Box 1492
Washington, DC 20013
(703) 893-6061 (Voice and TDD) or (800) 999-5599 (Toll Free)
Contact: Carol Valdivieso (Project Director)

NATIONAL PARENT NETWORK ON DISABILITIES

The National Parent Network on Disabilities is a new coalition of many parent organizations in the states and communities and individual parents that was established in early 1990 in the nation's capital to provide a presence and national voice for parents of persons with disabilities. It is a successor organization to the National Network of Parent Centers, Inc. It is concerned with handicapped children / individuals of all ages. However the Network has strong links with those parent organizations which represent the needs of infants and toddlers.

National Parent Network on Disabilities
1234 Massachusets Avenue, N.W.
Suite C107
Washington, DC 20005
(202) 638-6736
Contact: Patty McGill Smith

SELECTED REFERENCES

American Academy of Pediatrics. *Proceedings from a National Conference on Public Law 99-457: Physician Participation in the Implementation of the Law.* Conference held in November, 1988. Co-sponsored by the Office of Maternal and Child Health, Public Health Service. Washington, DC.: Author, 1989.

Anderson, P., Fenichel, E. *Serving Culturally Diverse Families of Infants and Toddlers with Disabilities*. Washington, DC.: NCCIP, 1989.

Bailey, D. "Case Management in Early Intervention." *Journal of Early Intervention*. 1989 Vol. 13, No. 2.

Bailey, D. and Simeonsson, R. *Family Assessment in Early Intervention*.. Columbus, Ohio: Merrill Publishing Co., 1988.

Bailey, D., Simeonsson,R., Yoder, D., Huntington, G., "Infant Personnel preparation Across Eight Disciplines: An Integrative Analysis." *Exceptional Children*. In press.

Bailey, D. Buysse, V. Edmonson, R. and Smith, T. "Creating a Family Focus in Early Intervention: Professionals' Perceptions of Typical Practices, Ideal practices and Barriers to Change." Paper available from the Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill. Submitted for publication.

Barnett, S. and Escobar, C. "Economic Costs and Benefits of Early Intervention." Chapter 23 in Meisels and Shonkoff, eds. 1990. *op.cit.*

DOE/DHHS. Department of Education and Department of Health and Human Services. *Meeting the Needs of Infants and Toddlers With Handicaps. Federal Resources, Services, and Coordination Efforts in the Departments of Education and Health and Human Services.* A Report to the Congress. January, 1989. Available from the National Center for Information on Children and Youth with Handicaps. P.O. Box 1492 Washington, DC. 20013.

Dunst, C., Trivette., and Deal, A. *Enabling and Empowering Families: Principles and Guidelines for Practice*. Cambridge, MA.: Brookline Books, 1988.

Fox, H., Freedman, S., & Klepper, B. "Financing Programs for Young Children with Handicaps." Chapter 9 in Gallagher, Trohanis and Clifford, 1989, *op cit.*

Fox, H. and Yoshpe, R. "Medicaid Financing for Early Intervention Services." Paper available from Georgetown University Child Development Center, Washington, DC. June 1987. This paper is being updated.

Gallagher, J., Harbin, G., Thomas, D., Clifford,R. and Wenger, M. *Major Policy Issues in Implementing Part H-P.L. 99-457.* Working Paper. Carolina Institute for Child and Family Policy, UNC at Chapel Hill. October 1988.

Gallagher, J., Place, P., Shields, M. *The Generation of Family Policy Options.* Working Paper. Carolina Institute for Child and Family Policy. UNC at Chapel Hill. June 1989.

Gallagher, J., Trohanis, P., and Clifford, R. eds. *Policy Implementation & P.L. 99-457.* Baltimore, MD: Brookes Publishing Co., 1989.

Georgetown University Child Development Center. *Developing Culturally Competent Programs for Children with Special Needs*. Washington, DC.: Author. 1989.

Georgetown University Child Development Center. *Establishing a Medical Home for Children Served by Part H of Public Law 99-457*. An Issue Paper. Prepared as a result of a conference co-sponsored by the American Academy of Pediatrics and the Bureau of Maternal and Child Health and Resources Development. Washington, DC: Author, June, 1989.

Greenspan, S. and White, K. "The Efficacy of Preventive Intervention: A Glass Half Full?" *Zero To Three*. Bulletin of NCCIP. Vol. V, No. 4 April 1985.

Harbin, G. and McNulty, B. "Policy Implementation: Perspectives on Service Coordination and Interagency Cooperation." Chapter 30 in Meisels and Shonkoff eds. 1990, *op.cit.*

Harbin, G., Gallagher, J., Lillie, T. *States' Progress Related to Fourteen Components of P.L. 99-457, Part H*. Working Paper. Carolina Institute for Child and Family Policy. UNC at Chapel Hill. October, 1989.

Harbin, G., Terry, D., Daguio, C. *Status of the States' Progress Toward Developing a Definition for Developmentally Delayed as Required by P.L. 99-457, Part H*. Working Paper. Carolina Institute for Child and Family Policy. UNC at Chapel Hill. April, 1989.

Hauser-Cram, P., Upshur, C., Krauss, M. Shonkoff, J. "Implications of Public Law 99-457 for Early Intervention Services for Infants and Toddlers with Disabilities." *Social Policy Report*. Volume III, No.3. Autumn 1988. A publication of the Society for Research in Child Development.

Johnson, B., McGonigel, M. Kaufmann, R., eds. *Guidelines and Recommended Practices for the Individualized Family Service Plan*. Washington, DC.: Association for the Care of Children's Health. March, 1989. Prepared in association with NEC*TAS.

Koop, C.E., *Children With Special Health Care Needs: The Surgeon General's Report. Campaign 87*. Report of the Surgeon General's Workshop on Children with Handicaps and their Families, held in 1982. Washington, DC: Division of Maternal and Child Health, HRSA/PHS. June 1987.

Krauss, M., Jacobs, F. "Family Assessment: Purposes and Techniques." Chapter 13 in Meisels and Shonkoff, eds. 1990, *op cit.*

Martner, J., and McGrab, P. *Mental Health Services for Infants and Toddlers: A Three-State Perspective on the Implementation of Part H of P.L. 99-457*. November 1989. Available from the CASSP Technical Assistance Center, Georgetown University Child Development Center 3800 Reservoir Road, N.W., Washington, DC. 20007

McGonigel, M. and Garland, C. "The Individualized Family Service Plan and the Early Intervention Team: Team and Family Issues and Recommended Practices." *Infants and Young Children*. July 1988. Aspen Publishers.

Mental Health Law Project (MHLP). *The P.L. 99-457 Infant-Toddler Program: Guide to the Part H Law and Regulations*. 1989. Notebook: A publication of the Early Intervention Advocacy Network. Available from MHLP, 2021 L Street N.W., Washington, DC 20036.

Meisels, S. and Shonkoff, J. eds. *Handbook of Early Intervention*. Cambridge, Mass.: Cambridge University Press, 1990.

Meisels, S. and Wasik, B. "Who Should Be Served? Identifying Children in Need of Early Intervention." Chapter 25 in Meisels and Shonkoff, eds. 1990. *op. cit.*

National Center for Clinical Infant Programs. *Infants Can't Wait and Infants Can't Wait: The Numbers*. Washington, DC.: NCCIP, 1989. (a)

National Center for Clinical Infant Programs. *The Intent and Spirit of P.L. 99-457: A Sourcebook. 1989* (b). Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, N.W., Washington, DC. 20057. (202) 625-8410.

National Center for Clinical Infant Programs, Project Zero To Three. The Center has published three brochures specifically addressing parents' role in E.I. as follows:
(i) *Equals in this Partnership:* Parents of Disabled and At-Risk Infants and Toddlers Speak to Professionals. 1985 (ii) *Four Critical Junctures:* Support for Parents of Children with Special Needs. 1989 (iii) *The Open Door:* Parent Participation in State Policymaking About Children with Special Health Needs. 1988. These are available at no cost from the National Maternal and Child Health Clearinghouse, 38th and R Streets, N.W., Washington, DC. 20057 (202) 625-8410.

NEC*TAS. *A Bibliography of Selected Resources on Cultural Diversity*. 1989. Available from NEC* TAS, Frank Porter Graham Child Development Center, UNC at Chapel Hill.

O'Connell, J., Horn, R., Lenz, D., Schacht, R., Kitterman, M., *Arizona's Parents Speak Out*. Part III of a study prepared for the Arizona Interagency Coordinating Council. November 1989. Report available from the Institute for Human Development, Northern Arizona University, P.O. Box 5630, Flagstaff, AZ 86011.

Office of Technology Assessment (OTA).S. Congress. *Technology-Dependent Children: Hospital v. Home Care*. A Technical Memorandum. OTA-TM-H-38 Washington, DC: U.S. Government Printing Office, May, 1987.

Place, P., Gallagher, J., Harbin, G. *State Progress in Policy Development for the Individualized Family Services Plan (PL 99-457-Part H)*. Working Paper. Carolina Institute for Child and Family Policy. March 1989

Pizzo, P. "Parent Advocacy: A Resource for Early Intervention." Chapter 28 in Meisels and Shonkoff, eds. 1990, *op.cit.*

Pizzo, P. *Parent to Parent*. Boston, MA: Beacon Press, 1983.

Schrag, E. *Sensitivities, Skills, and Services: Mental Health Roles in the Implementation of Part H of P.L. 99-456*. Report prepared for the CASSP program, NIMH. Washington, DC: Georgetown University Child Development Center, 1989.

Shonkoff, J. and Meisels, S. "Early Childhood Intervention: The Evolution of a Concept." Chapter 1 in Meisels and Shonkoff, eds. 1990, *op.cit.*

Shonkoff, J., Hauser-Cram, P., Krauss, M., Upshur,C. "A Community of Commitment: Parents, Programs and the Early Intervention Collaborative Study." *Zero To Three*. Bulletin of NCCIP. Vol. VIII. No., June 1988.

Silverstein, R. "A Window of Opportunity" in *The Intent and Spirit of P.L. 99-457: A Sourcebook*. See NCCIP, above.

Smith, B. and Strain, P. "Does Early Intervention Help? *Digest # 455. 1988.* Available from ERIC Clearinghouse on Handicapped and Gifted Children. 1920 Association Drive, Reston, VA 22901.

Turnbull, A. and Turnbull, H. eds. *Parents Speak Out: Growing With a Handicapped Child.* Columbus, OH: Charles E. Merrill Publishing Co.

Vincent, L., Salisbury,. C. Strain, P. McCormick, C. and Tressier, A. "A Behavioral-Ecological Approach to Early Intervention: Focus on Cultural Diversity." Chapter 2 in Meisels and Shonkoff, eds. 1990, *op.cit.*

Wenger, M., McLaurin, J., Guild, P., Loda, F., Gallagher, J., Defriese, G., Rich, L., Bergsten, C. *Physician Involvement in Planning for P.L. 99-457 Part H: Interagency Coordinating Council Roles and System Planning Issues.* Working Paper. Carolina Institute for Child and Family Policy. UNC at Chapel Hill. November 1989.